

BLOOD TRANSFUSION THERAPY

Information for people with Diamond Blackfan anemia, and their families.

Why would a person with Diamond Blackfan anemia require blood transfusion therapy?

In Diamond Blackfan anemia (DBA), the bone marrow (the center of the bone where blood cells are made) does not make enough red blood cells. Red blood cells carry oxygen to all organs in the body. When the number of red blood cells is low, the organs in the body may not get the oxygen they need.

Blood transfusion is one way to increase the number of red blood cells. Some people only need blood transfusions now and then, when the hemoglobin is too low. Other people need regular blood transfusions (i.e., every 4–6 weeks) over a long period of time. This is called chronic transfusion therapy.

Some reasons that a person with DBA might receive regularly scheduled blood transfusions are:

- Other treatments (such as corticosteroids) have been unsuccessful.
- Side effects of other treatments are not tolerated.
- Anemia is very severe or causes complications.

What is blood transfusion therapy?

Blood transfusion means taking blood from a healthy person and giving it to someone else. Blood transfusion therapy means that a person receives regularly scheduled blood transfusions as treatment for a disorder. The blood is given through a vein or a permanent intravenous (IV) device. Blood transfusions are usually given every 4–6 weeks in a treatment center, hospital, or outpatient transfusion center.

What are the benefits of blood transfusion therapy?

After a blood transfusion, many people feel better, have more energy, and are able to participate in more activities. Children who receive blood transfusion therapy may grow better than they did while on other therapy.

What are the risks of blood transfusion therapy?

Negative side effects of blood transfusion therapy are uncommon but can include blood transfusion reactions, infections, the development of red blood cell antibodies, and iron overload in different organs of the body.

Blood transfusion reactions

Blood transfusion reactions are a problem caused by receiving blood. The most common problem is an allergic reaction. Allergic reactions may cause itching, hives or a rash, and rarely, may be associated with swelling, coughing, wheezing, and difficulty breathing. If these reactions occur, the doctor will recommend taking medicine before each transfusion.

Another potentially serious type of problem may occur up to 10 days after the transfusion. Call the doctor for the following: fever, rash, back pain, dark colored urine, or skin that is pale or has a yellow color to it (jaundice). These symptoms might suggest hemolysis, a form of rapid breakdown of the donated blood in the body called a “delayed transfusion reaction.”

For more information call:

1-877-DBA-NURSE





Infections

A common concern about blood transfusion therapy is the risk of getting an infection from a blood transfusion. Blood centers make every effort to assure that the blood supply is safe. The blood center will not accept blood from anyone who does not meet all of the requirements for healthy blood donors.

In addition, the blood is thoroughly tested for all of the viruses and bacteria that we currently know can be passed from one person to another through blood. Vaccination will also help prevent certain infections like hepatitis A and B.

It is important to remember that the blood supply in the United States is very safe, so passing infections through blood transfusion is extremely rare.

Red blood cell antibodies

Everyone inherits certain red blood cell traits, just as we inherit eye color and hair color. If a person receives blood cells with traits that do not match their own, the body may reject the blood cells and make an “antibody” to them. This antibody would destroy any blood that the person receives in the future that contains the same trait.

Red blood cell antibodies can also cause a transfusion reaction and make it difficult for the blood center to find blood that will work. To prevent these antibodies from forming, the blood center identifies the special red blood cell traits in the person receiving blood and then finds donors that match it very closely.

Iron overload

Iron overload occurs following frequent blood transfusions. All red blood cells contain iron. The body uses as much iron as it needs, but it cannot get rid of the iron it does not need. The extra iron received during each blood transfusion is stored in organs such as the heart, liver, pancreas, and endocrine glands. Without treatment, this iron would continue to build up and eventually damage these organs. When receiving blood transfusion therapy, the person’s growth and development, iron levels, hormone levels, and the function of the body organs will be monitored very closely to help prevent serious damage. The doctor may recommend going to certain specialists to help monitor any damage. Anyone having blood transfusion therapy should not take vitamins or supplements that include iron because these also can increase the amount of iron stored in the body. It may be necessary to take medicine, called chelation drugs, to help remove excess iron from the body.

Important Things to Remember:

- Ask questions. Make a list ahead of time to discuss with the doctor at your next visit.
- Be your own advocate because many doctors are not familiar with DBA and its complications.
- Do your homework and be part of the decision-making process.
- Get the hepatitis B vaccine before or shortly after starting blood transfusion therapy.
- Have a yearly medical exam to measure overall health, iron levels, and body organ function.
- If you decide to have a permanent IV device (e.g., Infuse-a-port, Port-a-cath) inserted for blood transfusions, talk with the doctor about what type of device is best. Some diagnostic scans cannot be done if you have a metal port.
- Find out about health insurance coverage for transfusion therapy. This type of treatment can be expensive. Discuss any concerns about health care coverage with your doctor and social worker.
- Ask for help. Support can come from friends, family members, doctors, and nurses on your medical team, or DBA organizations.
- Stay positive! Remember, you are not alone. There are people around the world, just like you, living with DBA.